SRUK Research Priorities

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Introduction

An important part of SRUK's work is to support innovative research into scleroderma and Raynaud's phenomenon in order to improve the lives of people affected by these conditions. SRUK formed from the merger of the Raynaud's and Scleroderma Association and Scleroderma Society; together these charities have invested over £10 million in scientific and medical research to date.

As part of SRUK's commitment to continue investing in research, a questionnaire was devised and sent to stakeholders in order to determine their priorities and inform the areas of research in which the charity will invest in the future. This survey has therefore given patients, relatives, carers, supporters, clinicians and researchers the opportunity to guide our research budget. It has also provided us with another way in which to evaluate the merits of the research proposals we receive.

Method

With input from our trustees and clinicians, we identified 13 research topics and asked stakeholders to rank them from 1 to 13, with 1 being the highest priority. It included some simple demographic questions (age, gender and a brief description of respondents' connection to SRUK).

The survey was available anyone with an interest in our operations. Paper copies were distributed to the 2072 members who receive our quarterly magazine. Links to the survey were available through Twitter, Facebook and SRUK.co.uk. The survey was also sent to 403 members who receive our e-magazine and 4,644 non-members who have signed up for the e-newsletter. An e-newsletter reminder was sent to an additional 1,173 people.

Results

The survey closed in the middle of February, by which time we had received 253 complete and 27 incomplete responses. One-hundred-and-eleven people filled in the online SurveyMonkey form and 169 paper forms were returned by post, 27 of which were incomplete. The 146 complete paper forms were added to SurveyMonkey.

Patients and supporters made up 96.15% of the total respondents. There were a very low number of respondents describing themselves as healthcare professionals (2.30%) and researchers (1.54%).

The ages of respondents were split into brackets (see Figure 1). Nearly 70% of people who responded were in the 60 or older age bracket. This to an extent reflects SRUK's membership base. The proportion is even higher if we only consider postal responses, with 90.34% being from people over 60. There were, however, surprisingly few people under the age of 30 who responded.
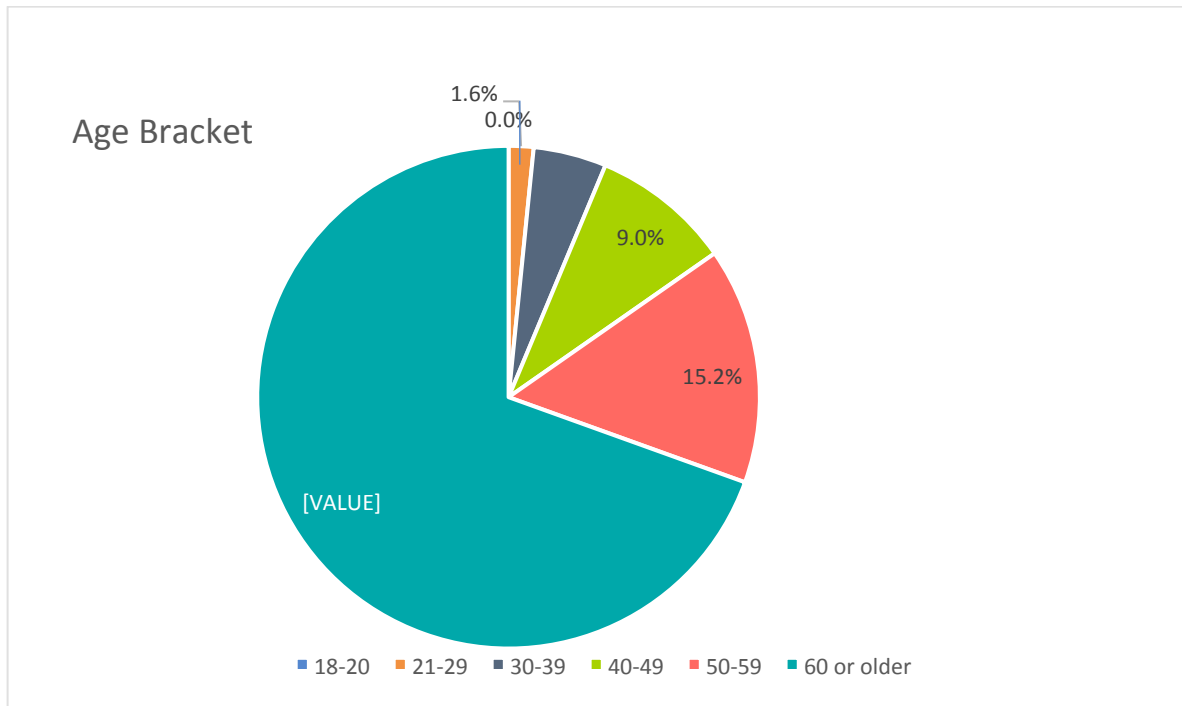
Figure 1: Breakdown of the ages of respondents

The gender split was 87% female and 13% male, with 1 person skipping this question. The answer was left open, however, so respondents could write their own response if they wished.

Priorities

There quite clearly popular and unpopular priority areas (see Figure 2). In this metric, the 5 most popular priorities are clear, with quite a large step down to the sixth average response. The top priorities were:

1) New and safer treatments
2) Detection of progression, complications and response to treatment
3) Improved and earlier detection and diagnosis
4) Causes of scleroderma and Raynaud's
5) Education of healthcare professionals

Health economics, epidemiology and financial impact all scored very low on average and were virtually never chosen as someone's top priority.
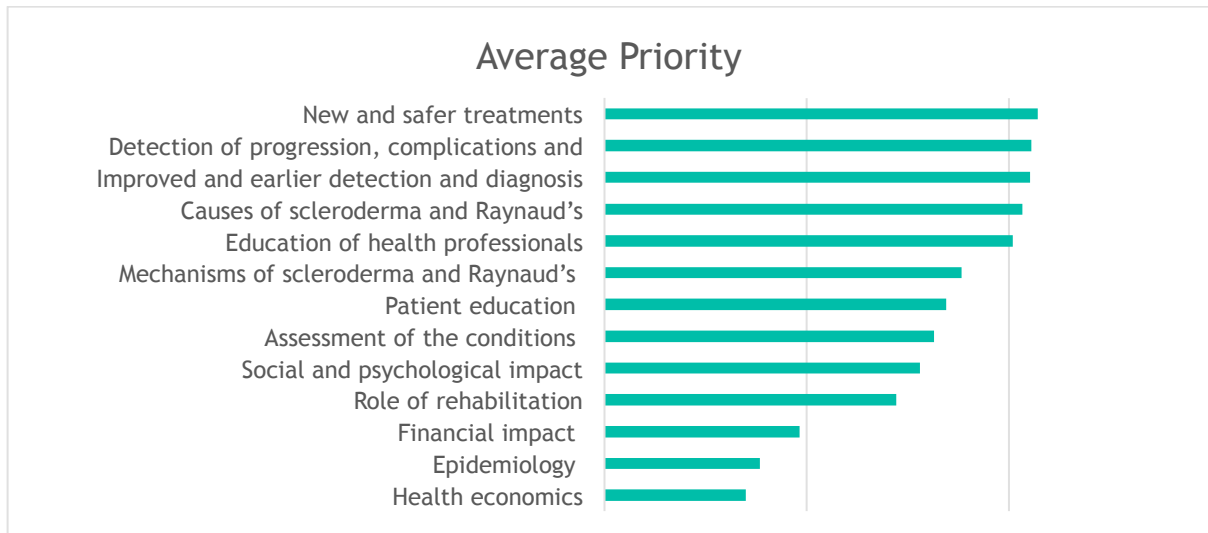
Average Priority

Category
New and safer treatments
Detection of progression, complications and
Improved and earlier detection and diagnosis
Causes of scleroderma and Raynaud's
Education of health professionals
Mechanisms of scleroderma and Raynaud's
Patient education
Assessment of the conditions
Social and psychological impact
Role of rehabilitation
Financial impact
Epidemiology
Health economics

Figure 2: Average priorities (longer line = higher priority)

It is also worth discussing which areas were given the most top and bottom priority choices in the survey (see Figures 3 and 4). The top priority percentages closely follow the average priorities assigned to the options. The notable exception is that despite being only the fourth highest average priority, 26% of respondents picked researching the causes of scleroderma and Raynaud's as their number 1 priority. This is 6% more than new and safer treatments, which topped the average rating section. In this metric, the top 4 choices area clear, but from here it becomes difficult to pick fifth from sixth (see Figure 3). The discrepancy between the position of the "Causes" research in this metric suggests that people either felt it was the top priority or far further down the list, whereas "New and safer treatments" was in people's top 3 in over 50% of our responses.
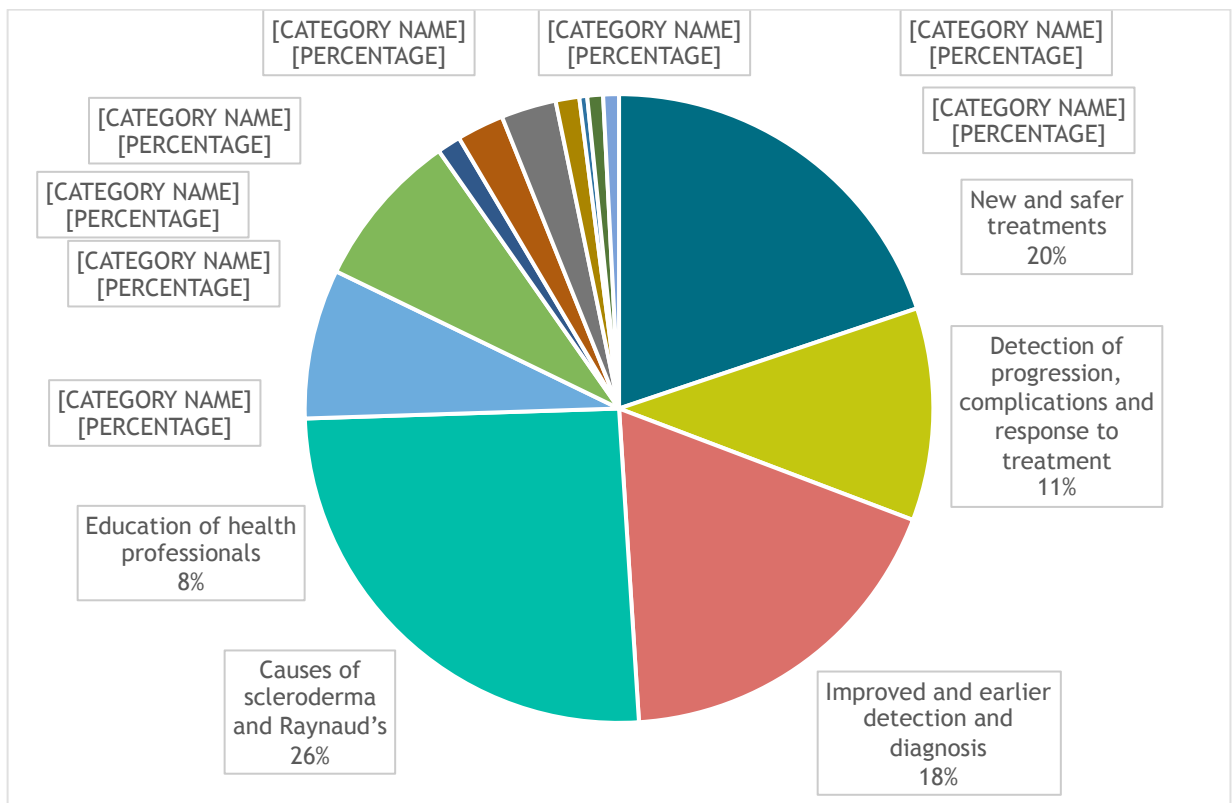
[CATEGORY NAME]
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[CATEGORY NAME]
[PERCENTAGE]

New and safer
treatments
20%

Detection of
progression,
complications and
response to
treatment
11%

Education of health
professionals
8%

Causes of
scleroderma
and Raynaud's
26%

Improved and earlier
detection and
diagnosis
18%

Figure 3: Number 1 priority choices

The results of the bottom priorities analysis (see Figure 4) are somewhat surprising, with "Epidemiology" being the bottom priority by more people than anything else. It is possible that the research support offered by the knowledge gained from epidemiology is not as highly valued by the respondents as more front-line treatment research.
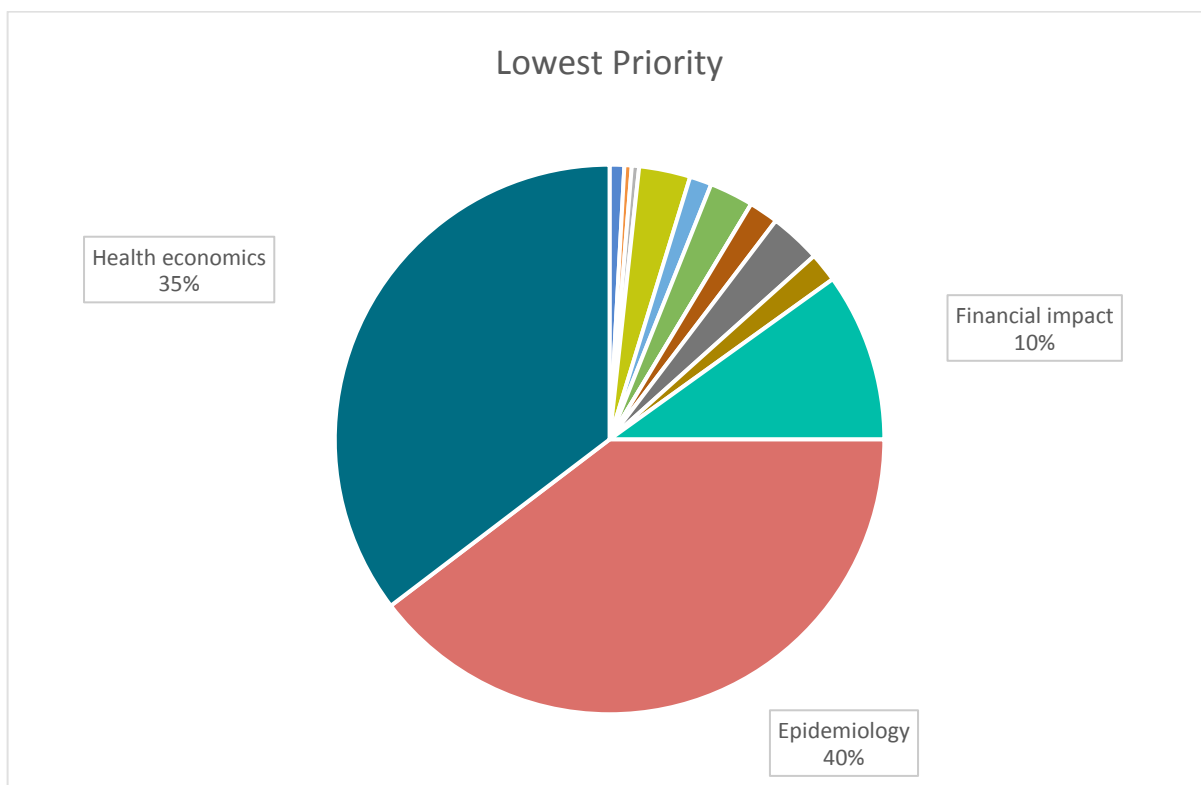
Figure 4: Number 13 priority choices

Many of the average priorities remain very similar as you move through the age ranges; however, in the 20-29 age range there was far more prevalence placed on "Social and psychological impact" as well as the "Financial impact". There are many possible reasons for this, but it is worth noting that only 4 respondents fitted this age range so the chance of points that are distant from other observations is higher.

Discussion

With a total of 253 responses, this survey has had by far the biggest response to any SRUK survey to date, demonstrating an increase in engagement and the level of passion that our supporters have about the research we fund. The proportions of people in each age group completing the survey reflect SRUK's membership, meaning that the survey effectively reached all of our members equally. The only exception was those in the 60 or over age bracket. Despite submitting almost 70% of responses, they are technically underrepresented as they make up 78.7% of SRUK's membership database (December 2016). Although no one under 20 and only 4 people in the 20-29 age range filled out the form, people under the age of 30 make up just 0.5% of our overall reach. These individuals had different priorities to the older respondents, but due to their small numbers their priorities had less impact.

Nine out of 10 surveys posted back to SRUK were completed by people in the 60 and over age range, therefore it is vital that SRUK continues to produce print as well as digital communications as older supporters are more engaged with print media. Surveys arrived in the post from about a week after the magazine was distributed to members until several days after the closing date.

There were a few notable trends relating to when people completed in the digital survey. The first few days in which the survey was available saw the most activity. This shows an engaged few who answered the survey as soon as it was available. This was followed quite a long tail off, showing good long-term availability of the survey. There were two surges in responses towards the end of the survey period, and these coincided with tweets about the survey. From this it seems that in order to receive more electronic responses, fairly regular social media signposting is required.

Priorities

Respondents rated causes, new and safer treatments, improved detection and diagnosis, the detection of progression, complications and response to treatment and the education of healthcare professionals as their top priorities. The order of these priorities could be debated, as there were varying levels of first choice selections by our respondents. A case can be made for "Mechanisms of Scleroderma and Raynaud's" being top, due to 8% of respondents selecting this as their first choice.

New and safer treatments

There appears to be significant feeling within our community about the way that scleroderma and Raynaud's are treated. There are many treatments for these conditions, however there is no cure and many of the treatments have problematic side effects. Immunosuppression, for example, requires patients to guard against possible infections, and there is the chance that a simple cold could keep such patients out of work for weeks. It seems clear from these results that our members want us to prioritise research into treatments with fewer side effects, and possibly into curative measures.

Detection of progression, complications and response to treatment

Detection of progression, complications and response to treatment is important as this leads to earlier, more effective treatment and, hopefully, there is a longer time before symptoms worsen. This also allows patients more time to prepare for possible lifestyle changes that could occur in the future.

Improved and earlier detection and diagnosis

Raynaud's and Scleroderma are difficult to diagnose in many scenarios due to the lack of common knowledge of the conditions, as well as a lack of standardized and widespread testing for them. Our members want to see us putting funding into improving this, as is also shown in the selection of "Education of Healthcare Professionals". With more widespread knowledge of these conditions, and by continuing to fund new diagnostic tests in this field, we can improve the rate and speed of diagnosis.

Causes of scleroderma and Raynaud's

Research into understanding the causes of scleroderma and Raynaud's may have a broader impact on detection, diagnosis, treatment and possibly even the prevention of triggering events. Previous research identified biological markers that indicate a predisposition scleroderma. Further research may help us to understand how these conditions are triggered or identify genetic markers to assist in early diagnosis or identify possible drug targets.

Education of healthcare professionals

Despite being relatively common, Raynaud's phenomenon is still a relatively unheard of condition. Scleroderma has an estimated incidence of just 20 per million,[1] and therefore many healthcare professionals are unaware of it. This can lead to misdiagnosis or late diagnosis, along with a lack of knowledgeable support from healthcare professionals. By

raising the profile of Raynaud's and scleroderma among healthcare professionals, and educating them as to what to look for and how to treat it, it should be possible to improve diagnosis rates and the quality of support and care received by patients.

How the survey results will be used

SRUK aims to identify the most relevant research projects and invest funds where they will have the greatest impact and best reflect the needs of our community. This was the reason we surveyed our stakeholders. The research priorities identified will be used to inform the charity's research strategy.

The creation and publication of a research strategy is part of SRUK's application to become a member of the Association of Medical Research Charities. Membership is the hallmark of quality research funding and provides a number of benefits, including access to funding assistance and project support, a centralised computer system to keep track of research projects and publications, and more legitimacy when talking to corporate sponsors.

Reference

1. Jimenez SA. Scleroderma. *Medscape*, 22 November 2016. http://emedicine.medscape.com/article/331864-overview, accessed 31/4/17